

# Effect of Psycho-Educational Training Program for Parent's Having Child with Leukemia on Their Experience and Psychological Wellbeing

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#### **Abstract**

Leukemia is a significant public health and life-threatening problem for pediatric cancer patients. Family caregivers of cancer patients receive little preparation, information, or support to perform their care giving role. This study aims to assess the effect of psycho-educational training program to enhancing practice and psychosocial adaptation for parents caring child with leukemia. the study was conducted at day care and out patient clinic in pediatric hospital of Ain Shams University .the sample of this study consist of 60 parents and their children attended day care and out patient clinic in pediatric Hospital of Ain Shams University. Data were collected through three tool first tool .,Interview questionnairesheet: it is developed by the researchers to collecting data regarding socio-demographic characteristics about patients and family caregivers , family knowledge about leukemia and family practice regarding care child with leukemia 2<sup>nd</sup> toolis Ryff'spsychological Well-Being Scales (PWB).third tools is Caregiver strain Index (CSI).the results reveleaved that was significant improvement in familyknowedge and practice ,as wellas were significant decrease in the stress level after Pogrom intervention andthere was a significant difference .Regarding psychological wellbeingbefore and after program intervention.thepresent recommended that Further research is necessary to understand the mechanisms through which parents cope with the strain of parenting a cancer survivor and how parenting stress in this parents influences both physical and mental health.

**Keywords**: leukemia -parent – stressors – adjustment – psychological wellbeing

#### Introduction

Childhood cancer is an increasing and prevalent type of chronic disease worldwide. Leukemia is one of the most common cancers in children under 15 years of age and represents 25% of all cancers in children. Like other chronic diseases, it causes many physical and mental problems for the caregivers, who are mainly parents, and makes parents show various levels of anxiety, shock, depression, disappointment, and denial during initial stages of the diagnosis of childhood (Gelesson, et al., 2014)

In recent years, the care giving responsibilities of family members have increased dramatically, primarily because of the use of toxic treatments in outpatient settings, the decline in available health care resources, and the shortage of health care Providers. Northouse, et al., (2010) . Tasks undertaken by family caregivers can be identified as either direct care or indirect care. Direct care encompasses tasks that are carried out with the patient directly while indirect care tasks are done on behalf of the patient by the family caregiver, such as paying bills. The role of the family caregiver changes as the condition and treatment strategies of the patient change. Kim, Baker, & Spillers., (2007). Family caregivers of cancer child have participated in a limited number of intervention programs, but these programs have focused almost exclusively on improving patient outcomes (e.g., symptom management, quality of life) with less attention directed toward the needs of family caregivers. Family caregivers have psychosocial needs that must be addressed so they can maintain their own health and provide the best care possible to the patient. Bishop, Beaumont, and Hahn., (2007)

Parents of pediatric cancer survivors often face residual effects of the disease and its treatment, plus the risk of newly emerging late effects or disease recurrence, that require significant long-term follow-up and care. In addition to concerns about physical health, pediatric cancer survivors often experience late effects including cognitive and learning deficits. These concerns require vigilance and action on the part of the parent to identify and meet their child's unique academic and social needs .Hardy,etal., (2008)

Psychological well-being includes the way people used to evaluate their lives in the present and in the past; so, these assessments cover the emotional reactions of People to events, moods, and judgments related to the way they live their own lives .Gómez,et al.,(2010)

# Significant of the Study

Leukemia is the most common malignancy in children .accounting for almost one third a newly diagnosed pediatric cancer case .the annual incidence, is approximately four case per 100,00 children per year in national cancer institute ,Cairo university ,Egypt. All constitute 30% of all pediatric malignancies. Numerous stressors for parents of survivors, including stress related directly to the leukemia, such as secondary illness, disabilities,



attention deficits, and loss of normal life and activities, as well as parenting stressors, such as ongoing feelings of grief, loss and uncertainty. Moreover, these stressors remain salient sources of distress and considerable strains on family resources well after treatment is completed. Family caregivers, along with assuming their new roles and undertaking these new tasks, must also deal with their usual daily life responsibilities as well as Parental stress and distress continue well past the completion of treatment, which suggests parents struggle with adapting to the "new normal" and continue to have fears about the long-term health and wellbeing of their child. Overall psychological health indicated an increase in Psychological symptoms, such as depression, anxiety, and emotional distress as caregivers remain in their care giving roles for longer periods. Caregivers have shown even higher distress levels than leukemic patients themselves. Enhancement of the parents' knowledge, skills about the problems and needs of their leukemic children has an important effect on family support, leading to a significant increase in the quality of life of these children, and promote psychological health for family members, so that our study aiming to implementing and evaluating the effect of psycho-educational training program on parents skills, psychological well being and buden of caring child with leukemia

#### Aim of the study

This study aimed to assess the effect of psycho-educational training program to enhancing practice and psychosocial adaptation for parents caring child with leukemia.

# This aim will be achieved through

- 1. Assessing parents' skills provided to their children(infection control, fever anemia s, weakness, worry, angry, nutrition, and side effect of chemotherapy)
- 2. Assess psychological impact and burden of caring child with leukemia on parents caregivers
- 3. Implementing training program to enhance parent's practice and adaptation to child illness
- 4. Evaluating the effect of this psycho-educational training programon parents skills, psychological well being and buden of caring child

# **Hypothesis:**

Intervention training program havepositive effec on the experience and psychological well being for parents caring child with leukemia

#### Research design:

The present study is " a quasi experimental " research designed to evaluate the psycho-educational training programon parents skills, psychological well being and buden of caring child

# **Setting:**

This study was conducted at day care and out patient clinic in pediatric hospital of Ain Shams University.

# Sample

The study was included apurposive sample of 60 parents and their children attended day care and out patient clinic in pediatric Hospital of Ain Shams University.

Total number of children with leukemia. Affiliated to day care and out patient clinic in pediatric Hospital of Ain Shams University studies that attending regularly twice / week for receiving treatment.

# Inclusion criteria for children with leukemia ' were:

- 1. Child diagnosed with leukemia.
- 2. Pre-school and middle school age children 3-12 years.
- 3. Sex: both sex (males and females)
- 4. Free from others neurological disorder or chronic physical disease
- or handicapped (through checking the child chart).
- 5. Attended the previously mentioned settings regularly

# Inclusion criteria for parents care givers:

- 1. Educational level for parents (at least can read and write).
- 2. Parents who give direct care to the child (nuclear family)
- 3. Involved in the care of cancer patients (at least 2-3 hour per day)
- 4. Aged > 18 years and including both genders
- 5. Are willing to participate.
- 6. Exclusion for caregivers who have Psychiatric problems



#### 3. Tools of data collection

# • Interview questionnaire sheet:

It was developed by the researcher; this sheet was collected from parents and child medical files. It was divided into three parts, as the following:

**Part 1:** Socio- demographic characteristics of the studied parents of children suffering from leukemia. It includes descriptive data regarding the parent's age, sex, number of Children, occupation, level of education, and monthly income.

Part 2: Characteristics of the studied children with leukemia. It includes a descriptive data regarding the child age, sex, order and duration of illness

#### Part 3:

A- Assessing the parent's knowledge regarding the meaning, causes, signs, and treatment methods of leukemia B- Assessing the parent's practice skills for child suffering from leukemia. It is

adopted from HASAN, HUSSEIN and HASHIM, ((2012)

• Caregiver StrainIndex (CSI)It is originally developed by Robinson, (1983) to measures strain related to care provision. It is consist of a 13-question, including major

domains: Employment, Financial, Physical, Social life and Time.

# Scoring system:

Each item has a score of zero if the answer is "No" and (1) if the answer is "yes".

A score of (7) or higher indicate higher level of stress.

• Ryff's Psychological Well-Being Scales (PWB)It is originally developed by Ryff's, (1989) to measure caregivers' psychological Well-being. It is consist of by the 18-item. The six concepts assessed by this scale (Autonomy, Environmental mastery, Purpose in life, Personal growth, positive relations with others and self-acceptance)

# **Scoring systems**

The items were scored on a 6-point Likert scale ranging from (1) strongly disagree to (6) strongly agree. Reverse-scored phrased items: 1, 4, 5,8,15,6,17 &18. Higher scores indicate better psychological well-being. The maximum total score possible is 108, and the minimum is 18.

#### Reliability of tools

The reliability of the tools that was assessed through measuring their internal consistency by determining Cronbach alpha coefficient, proved

	No. of	Cronbach Alpha Coefficient
Tools	items	Scale reliability
Caregiver Strain Index	5	0.76
Ryff's Psychological Well-Being Scales	6	0.91

**Pilot study:** The pilot study was carried out in. It was conducted on 10 % (they are executed from the study sample) from the total sample in order ensure the clarity of questions, Applicability of the tools and the time needed to complete them and perform the required modification According to the available resources.

# Results of pilot study

The researchers omit burden scale

# **Second: Designing phase:**

According to implementation of assessment tools to collect data regarding to parents' knowledge, skills about caring child, stressors facing parents and impact of stressors on their psychological well being the researhers desgin the programe sessions.

# Third: Implementing phase:

**Psycho-Educational Training Program** for parents was implemented in (20) sessions; each is different from each to another regarding its content.

**The initial '1st' session:Interviewing**: Each parent was interviewed individually to collect pre- assessment data through the data collection tools that mentioned before. This data were obtained at the 1st session to obtain the baseline data. Each session was based on health education and counseling sessions. During the initial session the researchers explained the aim of the study, meeting time which was twice / week. This session aim to establish therapeutic relationship with the parents, explaining objectives.

The '2<sup>nd</sup>' session: It is aimed to identify meaning of leukemia, what causes leukemia

The '3<sup>rd</sup>' session: It is aimed to identify symptoms of leukemia.

The '4<sup>th</sup>' session: It is aimed to clarify how does the doctordiagnosis leukemia and How is leukemia treated.

The 5<sup>th</sup> session: It is aimed to illustrate phases of treatment and types of treatment

The '6<sup>th</sup>' session: It is aimed to describe side effect of treatment, parents apply methods to overcome side effect



of treatment

The '7<sup>th</sup> session: It is aimed to review, phases of treatment and methods to overcome side effect of treatment.

The '8th session: It is aimed to the parents' apply guidelines to early detect and prevent of infection for child

The '9<sup>th</sup>' session: It is aimed to the parents' apply guidelines for normal growth and developmentandacting out activity to the child that will maintain adequate nutritional intake.

The 10<sup>th</sup> session: It is aimed to the parents' acting out activity to manage side effect of treatment such as fatigue, nausea, vomiting, a diarrhea hair loss and mucositis.

The 11<sup>th</sup> session: It is aimed to describe impact of leukemia on child (physical, psychological &social)

The '12<sup>th</sup>'session:It is aimed to the parents assess impact leukemia on child design guidelines for lessen the impact the leukemia on child

The '13<sup>th</sup>' session: It is aimed to describe impact of leukemia on family as whole, determine needs & problems of the parents.

The '14<sup>th</sup>' session: It is aimed to discuss the family coping with stress in general and way of coping with child illness particularly.

The '15<sup>th</sup>' session: It is aimed to assess sings of anxiety among parent's caregivers and parents follow general guidelines for controlling their anxiety.

**The '16<sup>th</sup>' session**: It is aimed to assess signs of depression among parent's caregivers and parents follow general guidelines for controlling their depression.

The '17<sup>th</sup>' session: It is aimed to parents' apply methods that overcome negative thought

The '18th' session: It is aimed to parents' practice deep breathing exercise.

**The '19<sup>th</sup>' session**: It is aimed to list types of relaxation techniques, apply types of relaxation technique and use religion activity and social support to cope with leukemia stress.

The '20<sup>th</sup>' session: It is aimed to summarize program and its objectives and do post evaluation.

Methods of teaching: Group discussion.

Role play.

open discussion.

Small group activity.

**Demonstrations Practical work** 

Media: Hand out

Posters

**Pictures** 

Real situation

Real object

Flipchart

# Field Work

The process of data collection was carried out in the period from June 2014to the end of end of August 2014, the researchers attended day care and out-patient clinics from 9.00 am to 12.00 pm .for three days/ week to collect data till the sample size reached the determined number

### **Ethical consideration:**

The ethical research considerations in this study included the following:

- The research approval obtains before training program implementation.
- Subjects are allowed to choose to participate or not participates 'voluntary participation' and they have the right to withdraw from a study any time without penalty.
- The researcher describes the objective and aim of the study to subjects.
- Maintain confidentiality and anonymity for every selected child or parent who involved on the study sample.
- Clarifying that all information will be used for scientific research only

# Statistical design

An IBM compatible PC. Was used to store and analyzes the data and to present the important results calculations were done by means of statistical software

Package namely "SPSS". The statistical process used in the analysis included:

The statistical process used in the analysis included:

- Simple frequency tables.
- Paired "t" test for comparing quantitative continuous data before and after sessions.

# The statistical process used in the analysis included:

Non significant (NS) if P value > 0.05

Significant (S) if P value < 0.05

High significant (HS) if P value < 0.01



#### Results

Table (1) Shows that the mean age of children in the study was 7.07±2.56

**58.3%** of them were boys. As for child ranking, **38.3%** of them had third ranking in their family. **78.3%** from the children diagnosed from less than one year and **63.3%** of them treated by chemotherapy. In relation to the educational level of child with leukemia children, **63.3%** of them were in elementary school.

**Table (2)** Shows that the mean of parents' age included in the study was 34.4±7.0 and 91.7% were females. Concerning parent's education, 58.3% of them were having basic education. and 10% only were university graduates. In relation to their occupation, 50% were house wives. Regarding to their residence 73.3% live in urban area. 13.3 from the families have seven members the majority of them (93.3) with insufficient monthly income for their needs.

**Table (3)** Show that highly statistically significant relations between Parents knowledge regarding leukemic disease characteristic, diagnosis, symptom, treatment, side effects of chemotherapy before and after intervention. Also the table show statistically significant relations regarding definition, disease process and frequent infection before and after intervention mean while insignificant relations regarding causes, Bone marrow transplantation. There was significant relation between leukemia and child development, experience anxiety and depression, healthy nutritious diet, academic achievement and chronic disease before and after intervention.

**Table (4)** Show that the highly statistically significant relations between parents caregiver's practices regarding caring child with leukemia disease before and after program. it was observed in, using soft toothbrush, fluid intake, dealing with nausea, exercise, social activity and intake of tea and café.

**Table** (5) Show that parent's prone to different stress. Highly statistically significant relations were notice in sleep disturbance, changes in personal plans, and demands on my time, behavior upsetting, and work adjustments.

**Table (6)** shows that there were significant decrease in the stress level after Pogrom intervention

**Table (7-a)** The table show that 33.4% of parents strongly agree that "I gave up trying to make a big improvements or Changes in my life a long time ago, regarding to autonomy sub items. Meanwhile concerning to purpose of life and environmental mastery sub items 45 %&40 % strongly disagree that I live life one day at a time and don't really think about the future I am quite good at managing the many Responsibilities of my daily life. About personnel growth sub items 43.3% slightly agree that When I look at the story of my life, I am Pleased With how things have turned out. as well as same percent slightly disagree that "I like most aspects of my personality" concerning to self acceptance sub item. Finally regarding to positive relations with others sub items 28.3%moderately disagree that I have not experienced many warm and trusting relationships with others.

**Table (7-b) Table (7-b)** the table shows that highest propration of parents (46.7%) strongly agree that "For me, life has been a continuous process of Learning, Changing and growth as regarding Purpose of life sub items .concering to environmental mastery

sub items 45% of parents strongly agree" The demands of everyday life often get me down".about the autonomy subitems 33.4% of partents strongly agree that I have confidence in my opinions, even if they Are contrary to The general Consensus. as notice from the table 43.3% of parents Slightly agee that "When I look at the story of my life, I am pleased With how things have turned out regarding to personnel growth sub items while they are strongly disagree that "I like most aspects of my personality in their appraisal to self acceptance sub items. Finally 30% of parents strongly agree that People would describe me as a giving person, willing to share my time with others regarding to their estimation to positive relations with others sub items

**Table (8) as** obsrved from the table the was significant difference there was significant difference regarding psychological wellbeing before and after program intervention

#### Discusion

Parents to child with a life-threatening disease such as cancer are often deeply involved in the child's disease and provide extraordinary and uncompensated care.

The parents may take on a range of disease related tasks, e.g., provision of emotional support, physical care, treatment monitoring, and symptom management.

In addition, the caregivers also frequently takeover or assist with everyday tasks, such as cooking, housekeeping, and child care .These tasks can be emotionally, physically, socially, and financially demanding, and 10–50% of the caregivers experience considerable strain. Negative consequences of care giving, such as depression, anxiety, distress/stress fatigue and insomnia, have frequently been reported. Thus, care giving may have significant costs to the caregivers' own well-being.Education was also found to significantly predict psychological distress among caregivers of cancer patients. Knowledge and awareness of family's caregivers are vital in influencing their manners in handling and taking appropriate action to face a disease and managing stressors



# Socio- demographic Characteristics of child with leukemia

The results of present study shows that the highest percent of child with leukemia are boys in age group 6-<9. This result similar to ELwahab,etal., (2010) and Mousavi, Pourfeizi, and Dastgiri.,(2010) they assess incipience of leukemia in Egypt and Iran they found that leukemia is more prevalence in boys in young age less than 15 years old. About the duration of disease the result explained almost two third of patient have disease for period < 1 year. These results similar toEL-SAWY, et al., (2013) they assessing knowledge and home practices of caregivers having children with leukemia. They found two third of sample were mother. in the light of the present study, the result denotes that chemotherapy is the most prevailing treatment among child with leukemia. This results in accordance to leukemia foundation, (2010)

Regarding to the rank of the studied children it was found that leukemia was likely to be in the thrid child. This finding was disagree with *Nathan*, et al., (2003) who mentioned that the high incidence of leukemia occurs in the first or only children in the family .Mourad, F.H., (2012)

Socio- demographic Characteristics of Parents caregivers

The present study revealed that, the mean age of parents was  $34.4\pm7.0$  and half of them are in age group more than 35 years old. This reflects that parents in this age are mature enough to take responsibility for providing care for their children.

This results is similar to Nayak, et al., (2014) they assess "Quality of life of family caregivers of patients with advanced cancer. They found the majority of family caregivers age was 31-39 years. The results explained that the most of parents caregivers were mother half of them are house wife and .that results reflect that, the women are more able to take responsibly of caring sick child and give-up from other responsibility outside of home in order to providing care for leukemic child and other family members. This results is consistent with Saeui et al.,(2009) they conduct an Empowerment Program on the Competence of Caregivers in Caring for Pre school Children with Acute Leukemia Undergoing Chemotherapy in Queen Sirikit National Institute of Child Health. They found more half of caregivers were mother.

Also the results similar to Sitaresmi etal., (2008) they assess quality of life in Indonesian childhood with acute lymphoblastic leukemia, they the most of caregivers were mother. Concerning to educational level the result shows that half parent's caregivers have basic education. The result is similar to Alexander, (2009) reported that the majority of parents were not much educated, and he found that (25%) were illiterate and (45%) have their education till grade 10

This result is contradicting with Al-Jauissy, (2010) they assess Health care needs of Jordanian caregivers of patients with cancer and he found that more half of the sample have secondary education.

With respects to the residency areas our result found that less than three quarter of caregiver were coming from urban areas. This result is in accordance with EL-SAWY, et al., (2013) they found more half of caregivers were from urban area.

Also this result is contradicting with Al-Jauissy, (2010) who is found that the distance between participants' home and hospital ranged from 20 to 60 miles, and the average time required traveling from home to hospital. About the income level he results shows that almost of parents have inadequate income although their child was treating free, this may be due to the coast of transportation, the most mothers are house wife, expensive life demons in addition sometimes children need immediate medical management in private clinic. This result is agreement with Al-Jauissy, (2010) EL-SAWY, et al., (2013) they found family accompanying child to outpatient clinic in Jordon and Egypt were have low socio economic status.

# Parent's caregiver's knowledge about leukemic disease before and after training program

The present study denote that generally there significant difference in parent knowledge about leukemic disease after program intervention .this may be due the parent have a strong desire to overcome the child illness in order to keep healthy life style for their child in the futureas well as providing knowledge create some sense of security that things will be handled according to the mothers wishes. the result revealed that there was statistically significant relations between Parents knowledge regarding leukemic disease characteristic, diagnosis, symptom, treatment, side effects of chemotherapy before and after intervention. This maybe due tothe parents spend long times in visiting different physician clinic and pediatric hospitals until know their child diagnosis. Additionally they are interesting to control child disease in order to maintain family adjustment. As well as the researchers simplified the knowledge to the parents and frequent repeating from researchers.

This result is disagreement with HASAN. HUSSEIN and HASHIM, (2012) They found that (90 %,) of caregivers have deficient knowledge regarding causes and symptoms of the disease, and treatment.

The results clarified that there was a significant difference in family knowledge regarding definition and, disease process this may be due to the parents have been accepting child diagnosis, they were trying to identify the nature of leukemia, and it is impact on the child future. Also the result denote that there was significant difference regarding to child frequent infection, this may be related to children with leukemia may



undergo numerous medical examinations, tests, surgical operations, chemo- and/or radiotherapies, and other procedures, which can be painful, and increasing child possibility to infection. So that the mothers caregiver have been insist to acquire knowledge and skills in order to minimize the risk of infection to maintain better quality of life for his \ her child . These explanation consistent with Hashemi,andShokrpour, (2010) indicate that Parent education leads to better understanding of Leukemia, chemotherapy and their side effects, as well as the negative impact of this disease on children's quality of life.

Concerning to the parents knowledge regarding impact of leukemia on the child development, emotional status and academic achievement. The results explained there that their was significant difference after program intervention this may be due to the parents have been accept the child illness and they are struggle to lessen the impact of illness upon child due to leukemia and it is treatment impose, visible sideeffects such as hair loss, weight gain or loss, physical disfigurement, and repeated absences from school and peers, negatively impact children's social and psychological adjustment. This result similar to Kanjana, (2006) and Saeui, etal., (2009)they implement empowerment program for mother caring child with leukemia .they found that Mothers have a good knowledge regarding psychosocial impact of leukemia after program implementing. In the light of these results there was significant difference in family knowledge regarding to nutrition. This may be due chemotherapy and radiation treatment have side effect may include mucositis, fatigue, nausea and vomiting, diarrhea, pain, infection, and immune suppression .moreover the leukemia causing anemia .so that all mother insist to apply nutritional management to combat this side effect to decrease risk for infection and improving child growth .this explanation is agreement with Yilmaz, Aksoylar, and Kansoy. (2013) They assess The Informational Needs of Mothers about Physical Care at Home for Children who Underwent Stem Cell Transplants they found that mother need information regarding to monitoring of the side-effects and complications, and preventing or managing gastrointestinal system (GIS) symptoms, such as diarrhea, nausea and vomiting. Theresults denote there was insignificant difference in family knowledge regarding to causes and bone marrow transplant, this may be due to the disease already have been occurred. All mothers hope to be not arriving to the transplant stage.

# Parents caregivers practices regarding leukemia disease before and after training program

The results clarified generally there was a significant difference in family practice after training intervention this may be due to frequent demonstration from researchers as well as the mothers acquire accurate knowledge about leukemia and had been take active process to manage child illness and get ride from treatment side effect . This result in agreement with Sen-Ngam ,Pratepchaikul, and Phuwathananon., (2005) they assess maternal knowledge and practice development in caring for children with leukemia. They found was a significant improvement in mother after program implementing.

Also the results similar to Gelesson et al.,(2009) carried out a study at the chemotherapy outpatient clinic of the pediatric oncology institute in Brazil and indicated that, family caregivers of cancer patients had lack of practice and needed orientations about the disease,

The result clarified that there was a significant improvement in family practice regarding using soft toothbrush this may be due to the children with leukemia usually suffer from various oral complications, which may be due to the leukemia or due to the chemotherapeutic agents and/or radiotherapy. The complications may include some of the opportunistic infections like candidiasis, hemorrhage, mucositis, taste alterations and increased incidence of dental caries.

The result is not accordance with HASAN. HUSSEIN and HASHIM., ( (2012) most of caregivers have deficit practices regarding encourage their leukemic adolescent for brushing teeth, gums, and tongue. The result also disagreement with

National cancer institute., (2011) found that (92.5%)of caregivers have deficit practices to encourage their leukemic adolescent from brushing teeth, gums, and tongue after each meal and at bed time.

The results shows that there was highly significant relation between parents caregiver's practices regarding fluid intake, dealing with nausea, exercise, social activity and intake of tea and café. This may be due to the mother have been try to maintain healthy life style for their children through combat side effect of chemotherapy and caring disease sings. This result disagreement with

Al-Jauissy, (2010) and Sen-Ngam ,Pratepchaikul,and Phuwathananon.,(2005)They found family accompanying child with leukemia at outpatient clinic they have poor score level in practice. The result explain that there was a significant improvement in family practice regarding infection control measure, hand washing ,Clean vascular access site wear mask and avoiding sharp instrument. This may be due to the child with leukemia High risk to infection and mother insist to protect her\his child from infection to prevent disease worsening.

# Stressors among parent's caregivers before and after training program

The current study explained that the parent's caregivers have been experiencing different stressor this may be due to; they may live with continuous uncertainty about effectiveness and side effect of treatment. They become



more cautious about child diet and daily care. In addition Parents have their role extended in the context of pediatric care: they need to provide the emotional responses of the child and siblings, moderate their own emotions, establish satisfactory communication within the medical-hospital context. This explanation consistent withkars,etal., (2008) they assess parental experience child with acute lymphoblastic leukemia, they clarified the Parents have their role extended in the context of pediatric care: they need to provide the emotional responses of the patient and siblings, moderate their own emotions, establish satisfactory communication within the medical-hospital context, adapt to family routines, as well as deal with potential relapses.

The results denote that there was no significant difference regarding sub items Caring for someone is a physical strain this may be related to mothers spent all-time with child with leukemia in hospital or even at home, return home for house hold chore responsibility, mothers had concern about feeding their ill child, infection, cleanliness and remembering medicine, in the same time they are cautious about family members diet and daily care. Mother reported that they not have sufficient time for their self care. These results is similar to Aung, et al.,(2012) they assess psychosocial impact Childhood Cancer on the Familyfrom Singapore they found that found that the mothers (75%) reported a higher personal strain when compared to the fathers.

The results shows that there was highly significant difference regarding that Some behavior is upsetting this may be related to the parents are present during treatment procedure in addition the sick child have been experience change in self image, activity, diet. Parents are worry about prognosis of disease, fear from relapse. Most of parents have communication problems with doctors "said that the doctors not give them a clear picture about the child illness.

This results is consistent Kohlsdorf,andJunior.,(2012) they explained that cancer and its treatment can be stressful for families .parents respond to child diagnosis and treatment with different degree with stress that ,they upsetting from different factors such ad communication with health team members , child behavior and all of time have feeling of uncertainty about the disease .

In the light of stressors facing parents caring child there was a highly significant difference regarding sub items .it is upsetting to find the person I care for has changed so much from his/her former self. This may be due to the child undergoing treatment needs to deal with invasive procedures, side effects, the interruption of school and social routines, the delay of leisure activities, changes in diet, in self-image and self-conception. These result is agreement with Deh, etal., (2013) they explained Parents have been found to be psychologically affected by their child's diagnosis, treatment, side-effects of the treatment and child's health status.

The result shows the there was no significant difference regarding items. There have been family adjustments and I feel completely overwhelmed. This may be due the parents have been psychologically affected by their child's diagnosis, treatment, side-effects of the treatment and child's health status. They often need to change their family daily routine and some of their roles and responsibilities furthermore; financial burden financial recourses may be strained, as well as parents have fear of relapse in the future, they need to assimilate information, provide care to all family members and don't have time for themselves. This results is similar to Warner, et al., (2011) concluded that caring a child with Cancer as time consuming and therefore they did not have enough time to take care of other siblings, socialize with other people and/or even for themselves.

The result clarified that there was non- significant difference concerning to Care giving is a financial strain this due to direct medical costs such as costs of medical services obtained and non-medical costs such as costs incurred in receiving medical care, forexample transportation fees. Additionally most of mother lost their ability of work related to spent all time in care giving activities .this results is similar to Fletcher, Schneider, & Harry .,(2010) and Limburg et al.,(2008). Explain that The high cost of cancer treatment, particularly for those with no medical insurance cover, combined with other expenses have been found to be associated with high stress levels in parents caring for a child with cancer.

### Level of stress among parents caregivers before and after training program

The results explained that the most of parents on pre program phase have high-level of anxiety meanwhile level after program Implementing have been decrease this may be due parents have been accept child illness and ongoing I the treatment process as well as they are assimilate new information and practice a new skills that helping then in caring sick child additionally they have a complete faith in God,.

This explanation is supported by Nair, (2014 )stated that coping strategies are improved by seeking more information, concurrent with problem solving followed by efforts to restore emotional balance and religious beliefs.

This result is consistent with Saifan,etal., (2014) they assess perceived stress in mothers and fathers of a child with cancer in Jordan. They found that mother and father caring child with cancer have significant higher stress score than mother and father in general population; and mothers have high level of stress than fathers

Psychological well being among parents cargivers

The results clarified that parents have different level of psychological wellbeing this may be related to parents have been take a time to acknowledge to understand the treatment plan which is a long journey .parents experienced huge compromises in their ability to function in their roles as parents of their other children .most of



mothers said they going on dullness circle, They were unable to perform basic Caring tasks for other children including taking them to school, preparing food and so on. As well as depend on Allah to end their child suffering.

These result is similar to Wijnberg, et al., (2005) explain that in their study on small Taiwanese study compared the physical health of parents of children in active treatment and parents of children off treatment. They found that while parents of children off treatment reported better overall health and wellbeing than parents of children in active treatment, their health was poorer than a normative sample.

The result shows that there was a significant difference in parents' judgment regarding autonomy sub items In general, I feel I am in charge of the situation in Which I live" This may be due to in pre program, perceive the illness is fate from God.they not able to postpone illness but at time of diagnosis and treatment plan, they have active role in caring child with leukemia.

This result is agreement with Aung, etal., (2012) they found that the greatest proportion of the Malay/Indian parents reported the highest in the Mastery subscale. When they assess impact of childhood cancer on the family as a whole in Singapore. About environmental mastery sub items .the result clarified that there was there Was no significant difference in parent's judgment regarding items, the demons of life get met down .this may be due to the all mothers spent all of time with leukemic child either in hospital or at home .they return back to the home to perform other duties, such as preparing food, washing and providing care for other sibling mothers said caring sick child is time consuming they experienced physical health problems such as malaise ,weight loss and severe headache. This results consistent with Norberg, (2007) explain that parents of cancer survivors a period of 18 month found no improvement in parent physical and mental Wellbeing over time. The results illustrated that there is difference in parents perception regarding item, I am quite good at managing the many Responsibilities of my daily life. This may be due to parents have been accepting child illness and were tried to maintain family adjustment for combat child anxiety and depression as well as to assume other Inside family with helping from spouse and setting family priorities This result disagreement with Vrijmoet, et al., (2008) examined the relationship between pediatric specific parenting stress and family functioning in a sample of 116 parents of children treated for cancer. After controlling for treatment status (on vs. off treatment), they found that parenting stress related to caring for a child with a medical illness was associated with poorer family functioning.

The results shows that no significant change in parents perspective regarding items, I 'live life one day at a time and don't really think about the future. This may be due to The parents are overwhelmed by child care due to Childhood with leukemia is associated with loss of control in which parents have a very limited ability to influence events in the cancer experience. These perspective reflect that the parents have depression manifestation (they loss appreciation for the future) most of mother said they have uncertainty about the future. The best thing for families Is child recovery and this recovery by God why there are worry.

This result is disagreement with Anclair, et al., (2009) they assess fears among family members following their child brain tumors diagnosis and treatment. They found that parents of children with cancer were affected by the unexpected future outcomes and consequences of the treatment of their children. also the results contradicting with Saifan, et al., (2014) ) they assess perceived stress in mothers and fathers of a child with cancer in Jordan, they found that parents were not only affected by the short-term side-effects but also with the long-term side-effects of the treatment on the child. There was a belief that cancer treatment could have an effect on the child's future. Several parents were worried and anxious that the child would not return to normal as a consequence of the treatment.

Concerning to personnel growth and self acceptance sun items, the results show that there was no significant change in parent's perspective regarding items I look at the story of my life, I am Pleased With how things have turned out and I think it is important to have new experiences that challenge how you think about Yourself and the world. This may be due to parents have been struggle to manage the child illness such as searching for treatment, gain information about the disease, manage side effect of treatment coordinating efforts to manage daily activity for other family members as well as the child condition began to improve.

Most of mother said the family cohesiveness is increase since they were discover child illness, their spouse become more cooperative, and they gain social and financial support from relatives and other personnel

This result is consistent with Kim., Baker&Spillers, (2007)revealed that some parents reporting finding benefits, such as personal growth, as a result of their experiences with their child's cancer. This results is similar to Hutchinson, (2009) he was assess adjustment among 64 mothers caring cancer survivor, found that mother reported higher score on scores on the controlling situation.

Finally the result shows that no significant change in parent perception regarding to Sub item Maintaining close relationships has been Difficult and frustrating for me.

This may be due to the most parents were burden by the child care, other duties at homeand outside home. Most of mother said there is no time for socializing, they feel guilty for leave child alone .as well as they are afraid the child have infection when accompanying Child to social activity outside home.



This perception agreement with **Fletcher**, **Schneider & Harry.**, (2010) they reported that Parents of children with cancer reported that they feel lonely and isolated because of the treatment requirements and burden of care related to the child's illnessalthough there was a belief among parents that relatives and friends were supportive.

#### Conclusion

The present study concluded that.

The training program has a positive impact in improve family knowledge and practice but

There no significant change regarding stressor and psychological wellbeing. The present recommend that Establishment of counseling clinic for parent care giver of children with Leukemia

#### Recommendation

- Further researchesare necessary to understand the mechanisms through which parents cope with the strain of parenting a cancer survivor and how parenting stress in this parents influences both physical and mental health.
- Establishment of counseling clinic especially for parents of children with leukemia, to Promote care, reduce anxiety, and consequently, enhance quality of life

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# Tables Table (1) Distribution of children according to their socio- demographic characteristics

Item	No.	Percent %
Age (years)		
3-<6	16	26.7
6-<9	25	41.6
9 <u>&gt;</u> 12	19	31.7
Mean±SD		7.07±2.56
Gender		
Boy	35	58.3
Girl	25	41.7
Birth order:		
Only	2	3.3
First	6	10
Second	14	23.4
Third	23	38.3
Fourth	15	25
Duration of Disease:		
< 1 year	47	78.3
≥ 1 year	13	21.7
*Methods of Treatment		
Chemotherapy	38	63.3
Radiation therapy	21	35
Corticosteroid	15	25
Blood transfusion	23	38.4
<b>Educational level</b>		
Illiterate( preschool)	22	36.7
Elementary school	38	63.3



Table (2) Distribution of parents according to their socio- demographic characteristics

Items	No.	%
Gender		
Male (father)	5	8.3
Female { mother }	55	91.7
Age		
< 30	6	10
30-	23	38.4
35+	31	51.6
Mean±SD 34.4±7.0		
Educational level		
Read and write	10	16.7
Basic education	35	58.3
Secondary education	9	15
University	6	10
Family size:		
three	3	5
Four	14	23.3
Five	22	36.7
Six	13	21.7
Seven	8	13.3
Monthly income		
Adequate	4	6.7
Inadequate	56	93.3
Occupation		
House wife	30	50
Employed	15	25
Unemployed	15	25
Residence		
Urban	44	73.3
Rural	16	26.7



Table (3) Parents knowledge about leukemic disease before and after a training program

Table (3) Parents knowledge about leukemic		before an	program			
Items		pre		1	T	
Items	No	%	No	%	1	p-value
Leukemia is cancer of the body's blood	11	18.3	56	93.3	-1.027	.006
Leukemia is a disease characterized by <i>increased</i> numbers of white cells in the blood and bone marrow	7	11.7	43	71.7	-1.938	.000
Boys are high risk for Leukemia	3	5	50	83.3	917	.049
Heridatry is a main cause of leukemia	5	8.3	38	63.3	-1.064	.027
The definite diagnosis is made a by bone marrow examination	9	15	35	58.3	-3.328	.000
The most common symptom of leukemia is Swollen lymph nodes, enlarged liver or spleen	10	16	44	73.3	-2.408	.000
Bone painis another symptom of leukemia	11	18.3	46	76.7	-2.309	.000
Fatigue is a result of the disease process.	12	20	38	63.3	-1.349	.004
Leukemia can be treated by Radiation therapy only	14	23.3	33	55	-2.327	.000
Bone marrow transplantation can sometimes save patient's life.	14	23.3	51	85	205	.669
Leukemia is a disease which needs repeated hospitalization	18	30	14	23.3	-1.836	.190
Leukemia is a disease lead to frequent infection	17	28.3	47	78.3	-1.249	.004
Leukemia is delay the child development	5	8.3	3	5	-1.099	.898
Common side effects of chemotherapeutic agents are nausea ,vomiting and mouth ulcer	16	26.7	48	80	-1.857	.000
Child with leukemia experience anxiety and depression	28	46.7	32	53.3	141	.779
Child with leukemia prone to poor academic achievement	9	15	10	16	-2.602	.193
A healthy nutritious diet is helping child to cope with their disease and treatment	12	20	51	85	205	.669
leukemia is chronic disease	3	5	2	3.3	392	.691

The answer is not mutually exclusive



Table (4) parents caregivers practices regarding leukemia disease before and after training program

Items	Pre		Post			
					T test	P-
	no	%	no	%	1	value
Hand washing before and after preparing food.	18	30	53	88.3	466	.250
Check the mouth and tongue every day.	13	21.6	28	46.7	.141	.779
Encourage brushing teeth, gums, and tongue after each meal and at bed time	15	25	31	51.6	866	.101
Encourage brushing teeth with a very soft toothbrush.	11	18.3	36	60	-1.536	.003
Avoid sharp and hard material forms.	12	20	31	51.6	866	.101
Encourage adequate sleep of at least 8 hour each night.	10	16	30	50	528	.305
Increase fluid intake	9	15	16	26.7	2.416	.000
Avoid sharp and hard material forms.	16	26.7	43	71.3	136	.780
Avoid patient's contact with ill people	11	18.3	48	80	1.064	.233
Small meals and snacks when he/she has nausea.	16	26.7	24	40	2.743	.000
Encourage to 5 or 6 small meals and snacks instead 3 large meals.	8	13.3	33	55	-1.015	.052
Encourage to wear a hat or a cap for alopecia.	18	30	49	81.7	.626	.348
Avoid direct sunlight.	10	16	53	88.3	466	.250
Encourage deep breathing when feeling anxiety, and depression	15	25	48	80	1.064	.233
Encourage exercise.	7	11.7	35	58.3	-1.735	.001
Give large amount of fresh fruit and vegetables.	16	26.7	51	85	221	.682
Avoid staying in crowded and dusty areas.	10	16	49	81.7	.626	.348
Provide foods that are moist, soft and easy to chew and swallow	13	21.6	55	91.7	.159	.780
Encourage social activity.	3	5	18	30	2.150	.000
Avoid eating big meal before sleep.	15	25	44	73.3	517	.256
Limit intake of tea café intake	7	11.7	35	58.3	-1.735	.001
Using masking when contact with other outside home	11	18.3	46	76.7	.541	.380
Clean vascular access site	10	16	47	78.3	.793	.270

The answer is not mutually exclusive

Table (5) Stressors among parents caregivers before and after training program

Items	Pre	Pre		and pro	T test	p-value
	No	%	No	%	1	
sleep disturbance	18	30	15	25	2.933	.000
Caring for someone is inconvenient	34	56.7	30	50	.528-	.305
Caring for someone is a physical strain	56	93.3	43	71.3	136	.780
Caring for someone is confining	36	60	28	46.7	.779	.141
There have been family adjustments	24	40	46	76.7	.380	.541
There have been changes in my personal plans	12	20	12	20	2.342	.000
There have been other demands on my time	33	55	24	40	2.743	.000
There have been emotional adjustments	7	11.7	28	46.7	.779	.141
Some behavior is upsetting	47	85	17	28.3	1.951	.000
It is upsetting to find the person I care for has	49	81.7	11	18.3	2.145	.000
changed so much from his/her former self						
There have been work adjustments	24	40	24	40	2.743	.000
Care giving is a financial strain	33	55	33	55	1.015-	.052
I feel completely overwhelmed	44	73.3	28	46.7	.779	.141



Table (6) Level of stress among parents caregivers before and after training program

Items	Pre		Post		T test	p-value
	No	%	no	%		
High level of stress >7	45	75	20	33.3	-1.509	.060
Low level of stress <7	15	25	40	66.7	-1.921	.000

Table (7-a )Psychological well being among parents cargivers pre training program intervention

Table (7-a )Psychological well being a	Stron		Moderately				Slightly		Moderate				
	disag			gree		agree	Agr			ree		Agree	
	no	%	no	%	no	%	no	%	no	%	no	%	
Autonomy													
In general, I feel I am in charge of the situation in which I live	18	30	7	11.7	33	55	0	0	0	0	2	3.3	
I have confidence in my opinions, even if they Are contrary to the general Consensus.	16	26.7	11	18.4	14	23.3	15	25	4	6.6	0	0	
I gave up trying to make a big improvements or Changes in my life a long time ago. *	6	10	19	31.6	5	8.3	0	0	10	16.7	20	33.4	
Environmental mastery													
I tend to be influenced by people with Strong Opinions. *	7	11.7	6	10	10	16.7	17	28.3	7	11.7	13	21.6	
The demands of everyday life often get me down	5	8.4	4	6.6	8	13.3	13	21.6	10	16.7	20	33.4	
I am quite good at managing the many Responsibilities of my daily life.	24	40	12	20	16	26.7	2	3.3	0	0	6	10	
Purpose of life													
I live life one day at a time and don't really think about the future*	27	45	8	13.3	16	26.7	9	15	0	0	0	0	
For me, life has been a continuous process of Learning, Changing and growth.	2	3.3	13	21.7	5	8.3	11	18.4	12	20	17	28.3	
Some people wander aimlessly through life, but I am not one of them	7	11.7	18	30	0	0	0	0	18	30	17	28.3	
Personal growth.													
When I look at the story of my life, I am Pleased With how things have turned out.	3	5	6	10	5	8.3	26	43.3	9	15	11	18.4	
I sometimes feel as if I've done all there is to do in life. *	0	0	12	20	7	11.6	20	33.4	13	21.7	8	13.3	
In many ways, I feel disappointed about my achievements in life. *	10	16.7	7	11.6	10	16.7	9	15	10	16.7	14	23.3	
positive relations with others	3	5	11	18.3	9	15	10	16.7	15	25	12	20	
Maintaining close relationships has been Difficult and frustrating for me. *	6	10	9	15	8	13.3	13	21.8	8	13.3	16	26.6	
People would describe me as a giving person, willing to share my time with others.	8	13.3	13	21.7	5	8.3	10	16.7	15	25	9	15	
I have not experienced many warm and trusting relationships with others* self acceptance	15	25	17	28.3	13	21.7	5	8.3	10	16.7	0	0	
I think it is important to have new experiences that challenge how you think about yourself and the world.	3	5	9	15	5	8.3	21	35	5	8.3	17	28.4	
I like most aspects of my personality.	0	0	0	0	26	43.3	0	0	10	16.7	24	40	
I judge myself by what I think is important, not by the values of what others think is Important.	17	28.3	13	21.7	16	26.7	0	0	3	5	11	18.3	

<sup>\*</sup>reverse score



Table (7-b) Psychological well being among parents cargivers post training program intervention

Table (7-b) Psychological well being among parents cargivers post training program intervention												
				derate	~ .		Slightly				1	ngly
	di	isagre	disa	igree	disa	igree	Ag	ree	Agı		Agr	
	no	%	no	%	no	%	no	%	no	%	no	%
Autonomy												
In general, I feel I am in charge of the	10	16.7	7	11.7	3	5	5	8.3	17	28.3	18	30
situation in which I live												
I have confidence in my opinions, even if	8	13.3	0	0	12	20	12	20	8	13.3	20	33.4
they Are contrary to the general Consensus.												
I gave up trying to make a big improvements	7	11.7	13	21.7	15	25	9	15	4	6.6	12	20
or Changes in my life a long time ago. *												
Environmental mastery												
I tend to be influenced by people with	23	38.3	12	20	5	8.3	0	0	0	0	20	33.4
strong Opinions. *												
The demands of everyday life often get me	5	8.3	12	20	3	5	0	0	13	21.7	27	45
down												
I am quite good at managing the many	6	10	12	20	0	0	13	21.7	15	25	14	23.3
Responsibilities of my daily life.												
Purpose of life												
I live life one day at a time and don't really	15	25	15	25	10	16.7	15	25	5	8.3	0	0
think about the future*												
For me, life has been a continuous process	3	5	7	11.7	5	8.3	0	0	17	28.3	28	46.7
of Learning, Changing and growth.												
Some people wander aimlessly through life	6	10	9	15	12	20	20	33.4	10	16.6	3	5
, but I am not one of them												
Personal growth.												
When I look at the story of my life, I am	3	5	6	10	5	8.3	26	43.3	9	15	11	18.3
Pleased With how things have turned out.												
I sometimes feel as if I've done all there is to do in	4	6.6	10	16.7	0	0	14	23.3	11	18.4	21	35
life. *												
In many ways, I feel disappointed about my	13	21.7	9	15	4	6.6	11	18.3	7	11.7	16	26.7
achievements in life. *												
positive relations with others												
Maintaining close relationships has been	14	23.3	7	11.7	4	6.6	16	26.7	9	15	10	16.7
Difficult and frustrating for me. *												
People would describe me as a giving	13	21.8	9	15	8	13.3	4	6.6	8	13.3	18	30
person, willing to share my time with												
others.												
I have not experienced many warm and	9	15	12	20	14	23.3	0	0	14	23.3	11	18.4
trusting relationships with others*												
self acceptance												
I think it is important to have new	14	23.3	0	0	8	13.3	8	13.3	10	16.7	20	33.4
experiences that challenge how you think												
about Yourself and the world.												
I like most aspects of my personality.	0	0	0	0	26	43.3	0	0	10	16.7	24	40
I judge myself by what I think is important,	17	28. 33	13	21.7	16	26.7	0	0	3	5	11	18.3
not by the values of what others think is												
Important.												
***********												

<sup>\*</sup>reverse score

Table (8) Comparison between level of psychological adjustment among parent's caregivers before and after training program

uitei tiuli	iiig program	**				
Items	Pre	Post		T test	p-value	
	no	%	no	%		
Low psychological well- being18:<36	10	16.7	7	11.7	_3.032	.028
Mild psychological well being 36: <72	31	51.6	33	55	-2.327	.000
High psychological well being 72: 108	19	31.7	20	33.3	-1.509	.060

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